Oct 2022 **PINsider**

Moments from Sip n Saree event







President's Note

I am continuing to look for ways to grow the organization so that we can widen deepen our impact to the and community. Some efforts in flight include

- Hiring of contract resource
- Building Haldi Pustak (yellow book) •
- In person sales/meetups
- Youth volunteering
- Finding new voices
- · Supporting families with medical needs

Let me know if you want to connect with me on any of these or some other idea. Namitha Nayak

Our grant beneficiaries for this month are Grace to Change and DFW ATW. You can get more information about the beneficiaries at

www.gracetochange.org and www.dfwatw.org



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CHARITY SPOTLIGHT - HOPE

Hope Bandna joined our family when she was 14 months old. She was placed in my arms in an orphanage in Ludhiana, Punjab on September 16, 2019. After we came home it became clear that she was very medically complex. Hope was born with one small eye, one functioning kidney, eight beautiful toes, a missing piece of her skull, a large hole in her heart, and contractures in her elbow joints. Through many doctors' visits and tests we eventually found ourselves in a Geneticists office learning that our daughter had a change on the gene SMOC1 and combined with her other symptoms gave us the diagnosis of Ophthalmo Acromelic Syndrome (OAS). Hope is extremely rare. She is the only person known to be living with her variant of OAS and less than 40 people have been reported to have OAS since 1935. Hope is on her own journey and we find out new things about her condition all the time. OAS also causes Hope to be very small. She weighed a little over 1 lb at birth (750g) even though she was fully developed. Now at 4 years old, she weighs 24 pounds. The most important thing to know about Hope is that she's a kid! She just happens to see with her ears instead of her eyes. Hope is obsessed with Frozen 2 and can belt Show Yourself with all the conviction of Idina Menzel! She loves farm animals, dinosaurs, and birds. Her favorite toy of all time is a thermometer. She loves to play with her big sister, Lakshmi, who is also blind and adopted from Bengaluru. Hope LOVES to laugh!! And she loves to listen to others laugh and try to imitate them.

Our family has been greatly impacted by Hope's rare disease. I have had to step back from working to make sure that we can meet all of Hope's needs and get her to all of her therapies and appointments. Hope has 4-5 therapy appointments per week. She sees 14 different specialists and several of them we see every 3-4 months. There is always the possibility that Hope could have an emergency and be admitted to the hospital. She has had 4 hospitalizations since coming home in 2019 and 3 of those have been since May of this year.

Together we raised \$1191 for Hope!



